Mapping the cancer patient information landscape: A comparative analysis of patient groups across Europe and North America

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Abstract: Aim: Little is known about how patient groups provide information for patients. We invited 838 patient groups from Europe and North America to participate in an online survey.

Methods: The survey covered: (i) availability, accessibility and quality of information provided; (ii) methods by which patient groups communicate; (iii) ways in which patient groups acquire information and confirm its veracity/accuracy; (iv) how people access information online.

Results: European patient groups were significantly less effective in providing medically-related information than their North American counterparts in: Clinical Trials, Potential Causes of Cancer, Medical Research, Diagnosis/Screening, Symptoms, Treatments (all $p<0.0001$); Recommendations of best practice/care ($p<0.03$), Healthcare services($p=0.029$) and Complimentary Medicine ($p=0.01$). Clinical Trials($p=0.0006$), Medical Research($p=0.006$) and Diagnosis/Screening($p=0.0024$) were also areas where North American patients were more likely to require medically-related information.

Similar patterns emerged for non-medical information with Nutrition(<0.0001), Watchful waiting($p=0.0003$), Self-management of care($p=0.0003$), Prevention($p=0.002$) and Emotional issues($p=0.016$) being less effectively communicated by European patient groups. Nutrition was also an area where North American patients were more likely to require non medically-related information

The main barriers to accessing online information which showed differences between European and North American patients were: Perceived Lack of need, mainly due to faith in their doctors ($p=0.0001$); Limited Access to the Internet ($p = 0.0005$), Limited Computer skills ($p=0.02$); and Lower Income ($p=0.027$).

Conclusion: These results emphasise the more mature nature of cancer patient engagement/information provision in North America, providing

valuable insights and guidance to inform development of more robust and effective cancer patient information communication platforms in Europe.

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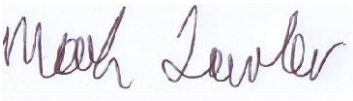
4th January 2018

Dear Editor

Please find enclosed our manuscript entitled **Mapping the cancer patient information landscape: a comparative analysis of patient groups across Europe and North America** which we hope you will consider suitable for publication in your journal

It represents to our knowledge the most comprehensive survey of cancer patient groups and how they provide knowledge to patients and individuals with an interest in cancer and the outputs from this research have the potential to enhance communication platforms for the provision of information (both medical and non medical) in Europe

Yours sincerely



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Mapping the cancer patient information landscape: a comparative analysis of patient groups across Europe and North America

Highlights

- European groups less effective in providing information than North American groups
- Significant barriers for cancer patients in accessing online information
- Results emphasise more mature cancer patient information provision in North America
- Results can inform more effective cancer patient information communication in Europe

Mapping the cancer patient information landscape: a comparative analysis of patient groups across Europe and North America

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Abstract

Aim: Little is known about how patient groups provide information for patients. We invited 838 patient groups from Europe and North America to participate in an online survey.

Methods: The survey covered: (i) availability, accessibility and quality of information provided; (ii) methods by which patient groups communicate; (iii) ways in which patient groups acquire information and confirm its veracity/accuracy; (iv) how people access information online.

Results: European patient groups were significantly less effective in providing medically-related information than their North American counterparts in: Clinical Trials, Potential Causes of Cancer, Medical Research, Diagnosis/Screening, Symptoms, Treatments (all $p<0.0001$); Recommendations of best practice/care ($p<0.03$), Healthcare services($p=0.029$) and Complimentary Medicine ($p=0.01$). Clinical Trials($p=0.0006$), Medical Research($p=0.006$) and Diagnosis/Screening($p=0.0024$) were also areas where North American patients were more likely **to require** medically-related information.

Similar patterns emerged for non-medical information with Nutrition(<0.0001), Watchful waiting($p=0.0003$), Self-management of care($p=0.0003$), Prevention($p=0.002$) and Emotional issues($p=0.016$) being less effectively communicated by European patient groups. Nutrition was also an area where North American patients were more likely **to require** non medically-related information

The main barriers to accessing online information which showed differences between European and North American patients were: Perceived Lack of need, mainly due to faith in their doctors ($p=0.0001$); Limited Access to the Internet ($p = 0.0005$), Limited Computer skills ($p=0.02$); and Lower Income ($p=0.027$).

Conclusion: These results emphasise the more mature nature of cancer patient engagement/information provision in North America, providing valuable insights and guidance to inform development of more robust and effective cancer patient information communication platforms in Europe.

Keywords: Cancer patient information; Cancer patient groups; Patient survey; Barriers to accessing information

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Introduction

Effective communication of information can underpin meaningful patient empowerment, while also embedding the patient's perspective in cancer control efforts[1-5]. Access to information is the underlying principle of the 1st Article of the European Cancer Patient's Bill of Rights, launched in the European Parliament on World Cancer Day 2014[6]. Tonio Borg, the European Commissioner for Health and Consumer Policy at the time, praised this 1st Article, emphasising how *"information is key to enable the patient to play an active role in his/her treatment, rather than just being a passive recipient[7]."* However, the increasing volume and fragmentation of information, originating as it does from an array of sources, can often overwhelm patients[8. 9]. This "information overload" can hinder the patient's appreciation of and contribution to the best option(s) for discovery science to be translated to patient-focussed clinical implementation. The exponential increase in data can confuse patients and citizens[10, 11], and this confusion, allied to potential distrust of particular information sources/providers, has led individuals to increasingly seeking help from patient groups. However, these patient groups may have been established to provide more general support, to focus on particular diseases, or to provide social assistance (including financial/legal help). Thus, they may lack relevant expertise to access, understand and provide co-ordinated, reliable, and robust information for the cancer patient.

Publication of research through articles in scientific/medical journals, and its subsequent public dissemination, often happens via main-stream media, where key messages can frequently be unclear and/or distorted[12-15]. The majority of research is published in English; thus patients in non-English speaking countries will receive translated information which may not have the same detail or provide the particular nuance intended in the original text. Decisions on what mainstream media publishes/highlights are usually based on what makes a "good" or "bad" news story; this may not necessarily reflect the interests/needs of cancer patients or health professionals[16]. Cancers affecting a smaller percentage of the population, the so-called "Cinderella cancers", tend to have lower media profiles than more highly prevalent and well-researched cancers such as breast, prostate and colorectal[17]. Innovative discoveries in rarer cancers such as pancreatic, lymphoma, sarcoma may not be disseminated as effectively as those for more common cancers.

Increasingly, patients use the internet to obtain health information about their disease[18, 19]. There is no single trusted source of information suitable for advocacy groups and patients[20]. Patients are faced with a plethora of websites and a babel of conflicting statements and claims. Thus, it is essential to better understand the strengths and weaknesses of current patient information provision from organisations serving the cancer community. In this study, we utilised a survey approach to gain important insights on the nature of the cancer patient information landscape.

Methodology

Data was collected from patient groups via an online survey. The survey was conducted in five languages: English, French, German, Italian, and Spanish. It was sent to all European patient groups listed in the world's most comprehensive database (PatientView) as providing information for cancer patients(n=767). To allow benchmarking of the European data, the survey was also sent to patient groups based in North America (n=71).

The survey covered five main areas:

1. Availability and quality of information provided by patient groups;
2. Methods by which patient groups communicate;
3. Methodology which patient groups employ to collect reliable information;
4. Criteria for standard setting for information being provided by patient groups;
5. Use of online resources by people with an interest in cancer.

Participants in European patient group survey

A total of 571/767 patient groups responded to the survey. The largest number of respondents came from the UK, representing 32% of the total groups surveyed. A total of 29% were umbrella groups for all cancers, 40% specialised in one or more common cancers, while 8% specialised in rare cancers. Nearly one quarter of groups (23%) had an interest in cancer, but cancer was not their main activity; the highest representation being from carer/family groups.

European groups deliver a variety of services to patients. Almost all (97%) provided information to patients. European groups also supplied information primarily in their national language, though 56% of all groups supplied information in English.

Participants in North American patient group survey:

A total of 68/71 patient groups responded to the survey. Of these, 87% were from the United States(US), with 13% from Canada. In total, 56% were umbrella groups for all cancers; 21% specialised in one or more common cancer, while 4% specialised in rare cancers. Nearly one fifth of groups (19%) had an interest in cancer, but cancer was not their main activity; the highest representation came from groups focusing on alternative therapies, carer/family groups and groups advocating for chronic disease.

North American groups deliver a variety of services to patients. All (100%) provided information to patients. Aside from English, North American groups supplied information in Spanish and French. Some groups employed translators to maximise the reach of their information.

Statistics

Two-sample z-tests for the difference between proportions were conducted. Significance was set at the 0.05 level.

Results

Survey Completion rates

A total of 838 patient groups (767 European/71 North American) with an interest in cancer were approached to participate. In the European arm, the survey was completed by 571 participating groups (Completion rate: 74%) (Table 1). A total of 68 completed the North American arm (Completion rate: 96%) ($p<0.001$) (Table 1).

Availability and Quality of information

Overall, availability and quality of information for patients with cancer was judged 'good' to 'excellent' by ~80% of respondents in Europe and just over 90% from North America($p=0.028$) (Table 2a) .

Provision of medically-related information was more limited in Europe compared with North America (Table 2b). Significant differences were detected in the following areas: Clinical Trials(29% v 78%, $p<0.0001$), Potential Causes of Cancer(39% v 68%, $p<0.0001$), Medical

Research(25% v 52%, p<0.0001), Diagnosis/Screening (57% v 86%, p<0.0001), Symptoms (61% v 86%, p<0.0001), Treatments (61% v 86%, p<0.0001), Recommendations of best practice/care (49% v 63%, p<0.03), Healthcare services 45% v 59%, p=0.029), and Complimentary Medicine (33% v 48%, p=0.01). Of these areas, Clinical Trials(p=0.0006), Medical Research(p=0.006) and Diagnosis/ Screening(p=0.0024) were also indicated as significant areas where North American patients were more likely **to require** medically-related information (Table 2d).

Provision of non-medically-related information was also more limited in Europe compared with North America (Table 2c). Significant differences were detected for information on Nutrition (55% v 83%, p<0.0001), Watchful waiting (27% v 48%, p=0.0003), Self Management of care (48% v 70%, p=0.0006), Prevention (52% v 72%, p<0.002), and Emotional issues (70% v 84%, p=0.0016), although information on Travel insurance was more likely to be provided by European patient groups (22% v 8%, p=0.007).

Interestingly, nutrition (43% v 66%, p=0.0003) was the only area identified where North American patients were more likely **to require** non medically-related information (Table 2e) while travel insurance (18% v 2%, p=0.0007) was the only area identified where European patients were more likely **to require** non medically-related information(Table 2e).

Methods of communication

Patient groups in Europe and North America remain heavily reliant on non-electronic forms of communication (Table 3a). The most popular form is by printed leaflets (74% of European-based groups v 89% of North American-based groups, p=0.007,). Patient- or public-focused ‘events’ were the next most popular form of communication (71% v 81% respectively) but did not reach statistical significance (p=0.082). Specifically from a patient perspective, annual patient meetings, conferences and summits were less frequent in Europe than in North America (50% v 69% respectively, p=0.003) Use of videos/DVDs (32% v 58% respectively, p<0.0001), Printed posters (43% v 61%, p=0.005), awareness-raising campaigns (41% v 55%, p=0.027), discussion groups(55% v 74%, p=0.003) and posted letters(40% v 53%, p=0.04) were also less utilised in Europe compared to North America.

When European and North American patient groups were asked to indicate the primary information channel most important to their activities, the top three choices selected by European-based organizations were ‘annual patient meetings, conferences and summits’ (25%), ‘websites’ (17%) and telephone help-lines (10%) (Table 3b). By contrast, in North America, the top three choices were ‘websites’ (33%) (p=0.001), ‘annual patient meetings, conferences and summits’ (16%) and face-to-face advice (11%) (Table 3b). Overall, North American organisations had a greater proportion of information resources available online (67% v 54%, p=0.042, Table 3c)

Gathering information

European-based and North American-based patient groups showed differences in their source of information about cancer (Table 4)’ the following were statistically significant: Academic Bodies (62% V 45%, P=0.008), Conferences/seminars (61% v 74%, p=0.036), medical journals (54% v 69%, p=0.019), government bodies (38% v 52%, p=0.03).Patient-specific information sources included accessing information from other patient organisations (43% v 63%, p=0.002) and online discussion groups (16% v 30%, p=0.004)

Setting standards for information

Approximately two-thirds (66% v 71% p=ns, Table 5) of patient groups stated that they regularly updated their information. Additionally 61% v 60%, (p=ns, Table 5) indicated that they obtained feedback from patients to assure trustworthiness/reliability of information. However, the majority of North American-based patient groups also took the added precaution of having their own medical/scientific advisory group check the information (48% v 60%, p=0.06). An online certification body check (14% v 24%, p=0.03) did reach statistical significance (Table 5).

Use of online resources

In Europe(67%) and North America(84%), people affected by cancer used websites as their main online resource to access information (p=0.004) (Table 6a). Email was also popular, with 43% v 71% of groups indicating that that they use it ‘most’ or ‘all’ of the time (p<0.0001), while use of social media (13% v 33%, p<0.0001) and electronic

newsletters(21% v 42%, p=0.0001) were also less popular in Europe compared to North America. (Table 6b).

Access to online cancer information remains difficult for older people, people who do not speak the country's main language, ethnic minorities, people with disabilities, and to a lesser extent European women (Table 6c). The main statistically significant barriers to patients seeking information online were: limited access to the Internet (84% v 67%, 0.0005); limited computer skills (85% v 74%, p=0.02); lower income (41% v 55%, p=0.027) (Table 6d). Additionally, both European and North America patient groups speculated that people do not access information online because they perceive either no need and/or have total faith in medical professionals (30% v 53%, p=0.001).

Discussion

Patient groups from Europe and North America that participated in this study deliver a wide range of support to cancer patients, including provision of cancer and cancer-related information. However, there were marked differences in the types of information that were made available and their mode(s) of delivery.

From a medical perspective, North American patient groups were statistically more likely to provide information on clinical trials, possible causes of cancer, medical research, diagnosis/screening, symptoms of disease, types of treatment, recommendations of best care/practice, availability of healthcare services and use of complimentary medicines. Our data suggest that a more comprehensive menu of information should be provided by European patient groups. Additionally, European patients could be signposted to sources of accurate information (e.g. Cancer Research UK, European Cancer Patient Coalition, country-specific cancer societies). A small number of sites providing consistent and regularly updated information, translated into a series of different languages, may provide a more reliable resource, such that European cancer patients and their carers can make more informed decisions on their care, including their ability to access innovative clinical trials.

A similar pattern emerged for issues not directly related to medical care, with North American patient groups statistically more likely to provide information on self-

management of care, nutrition, prevention, emotional issues and watchful waiting. Capturing and providing this increasingly important information can help empower patients to recognise and deal with some of these non-medical issues and access appropriate services that will support the cancer patient during his/her journey. This is particularly relevant for the >14 million cancer survivors in Europe[21], and as the number of people living with and beyond cancer increases, with an accompanying emphasis on care in the community, there will be a greater need for access to reliable information on sourcing appropriate services to help people cope with the physical, psychological or social sequelae of cancer[22. 23]. Travel insurance was the only area where European patients were more likely to receive information/advice, perhaps reflecting the lower propensity of American citizens in particular to travel outside the US.

While both European and North American patient groups tended to use the internet (through their website) as their major mode of communication (with North American patient groups ranking it as their most important form of communication), it was also apparent that North American patient groups made significantly more use of printed leaflets, posters, annual patient summits/conferences, videos/DVDs, awareness campaigns, discussions groups and posted letters to deliver their communication message(s). Providing information through different sources and through different media (e.g. print, video, internet) is an important component of a patient-centred communication strategy, as different patients may have preferred modes of receiving, processing and acting on the information that they receive.

Information sources varied between the survey constituencies but North American patient groups were statistically more likely to access information from conferences/seminars, academic bodies, government bodies, medical journals, other patient bodies and online discussion groups. They also employed certification bodies or expertise of medical professions (e.g. on their advisory group) to check the veracity of and ensure timely updates of information provided for cancer patients. It is important that robust, clear and unambiguous information is provided to patients and their carers, allowing them to make informed decisions that reflect the latest and most accurate information available.

Given the importance of providing online information sources, (with North American cancer patients statistically more likely to use websites, email, electronic newsletters or social media), we assessed the potential barriers to accessing information online. Limited access to the internet and limited computer skills were identified as the most statistically relevant barrier for European cancer patients, while North American cancer patients highlighted low income (which may indirectly identify challenges in relation to computer/online access) and a perceived lack of need due to confidence in their doctor/oncologist, as the principal barriers. Defining more precisely the computer skills and access gaps would allow more tailored training to be provided and online products to be designed for cancer patients, while also continuing to provide easy access to relevant material online, so that cancer patients have the opportunity to make an informed choice and participate in shared decision-making with their healthcare provider(s).

Our study has certain limitations. It captures a particular moment in time, and rapid developments in patient-focused information sources and tools mean that information delivery for patients and their carers are constantly being refined and improved. The exponential increase in social media sites and activities is not directly captured, with its significant potential to allow patients to self-aggregate and share experiences online. Additionally, as we surveyed organisations who provide information, rather than patients who access this information, it is a subjective survey, albeit one with clearly defined questions whose results can be quantitatively assessed

.

Conclusion

Our study identifies key components, activities and barriers that characterise the cancer patient information landscape in Europe and North America. It highlights how adoption of some of the best practices from North America may help create a buoyant information ecosystem that will enhance the European cancer patient's ability to make key decisions that positively influence their cancer treatment and improve their Quality of Life as people living with and beyond cancer.

Conflict of Interest Statement

All Authors indicate no Conflicts of Interest in relation to the current work

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1. RESPONSE RATE

Table 1: Response rate for European and North American participating organisations

	Europe (%)	North America (%)	z-value	*p*
Response rate*	74	96	4.1	<0.0001

**significant at the p<0.05 level*

2. AVAILABILITY AND QUALITY OF INFORMATION

Table 2a: Rating of overall availability and quality of information provided

	Europe (%)	North America (%)	z-value	*p*
'Good'/'Excellent'	80	91	2.2	0.028

Table 2b: Provision of medically-related information

	Europe (%)	North America (%)	z-value	*p*
Clinical Trials*	29	78	8.1	<0.0001
Possible causes of cancer*	39	68	4.6	<0.0001
Medical Research*	25	52	4.7	<0.0001
Diagnosis and Screening*	57	86	4.6	<0.0001
Symptoms*	61	86	4.1	<0.0001
Treatments*	61	86	4.1	<0.0001
Recommendations of best practice/care*	49	63	2.2	0.03
Healthcare services*	45	59	2.2	0.029
Psychosocial support	59	67	1.3	0.20
Palliative care	47	43	0.6	0.53
Complementary Medicine*	33	48	2.5	0.01

**significant at the p<0.05 level*

Table 2c: Provision of non-medical information

	Europe (%)	North America (%)	z-value	*p*
Self-management of care*	48	70	3.4	0.0006
Nutrition*	55	83	4.4	<0.0001
Prevention *	52	72	3.1	0.002
Emotional issues*	70	84	2.4	0.016
Quality of life	72	80	1.4	0.16
Relationships/Body image	50	56	0.9	0.35
Economic/Social consequences	49	53	0.6	0.53
Patients' rights	56	52	0.6	0.53
Employment issues	36	39	0.5	0.63
Patient complaints procedures	32	34	0.3	0.74
Spiritual issues	31	38	1.2	0.24
Watchful waiting*	27	48	3.6	0.0003
Legal issues	26	33	1.2	0.22
Problems of discrimination	24	31	1.3	0.21
Travel insurance*	22	8	2.7	0.007
Stigma	16	25	1.9	0.06

**significant at the p<0.05 level*

Table 2d: Requirement for medically-related information by people affected with cancer

	Europe (%)	North America (%)	z-value	*p*
Clinical Trials*	10	24	3.4	0.0006
Possible causes of cancer	38	43	0.8	0.423
Medical Research *	12	24	2.8	0.006
Diagnosis and Screening	61	75	2.3	0.024
Symptoms	63	67	0.6	0.517
Treatments	78	88	1.9	0.055
Recommendations of best practice/care	47	52	0.8	0.435
Healthcare services	44	54	1.6	0.117
Psychosocial support	42	48	0.9	0.344
Palliative care	27	17	1.8	0.075
Complementary Medicine	20	23	0.6	0.561

**significant at the p<0.05 level*

Table 2e: Requirement for non-medical information by people affected with cancer

	Europe (%)	North America (%)	z-value	*p*
Self-management of care	37	48	1.8	0.077
Nutrition*	43	66	3.6	0.0003
Prevention	38	45	1.1	0.263
Emotional issues	56	48	1.3	0.210
Quality of life	58	68	1.6	0.113
Relationships/Body image	36	27	1.5	0.141
Economic/Social consequences	40	36	0.6	0.524
Patients' rights	24	16	1.5	0.139
Employment issues	22	13	1.7	0.085
Patient complaints procedures	8	8	0.0	1.000
Spiritual issues	19	18	0.2	0.842
Watchful waiting	16	23	1.5	0.144
Legal issues	17	17	0.0	1.000
Problems of discrimination*	10	2	2.2	0.031
Travel insurance*	18	2	3.4	0.0007
Stigma	9	7	0.6	0.582

**significant at the p<0.05 level*

3. METHODS OF COMMUNICATION

Table 3a: Methods by which organisations communicated to patients

	Europe (%)	North America (%)	z-value	*p*
Printed leaflet*	74	89	2.7	0.007
Printed Posters*	43	61	2.8	0.005
Patient/Public events	71	81	1.7	0.082
Annual patient meetings/summits/conferences*	50	69	3	0.003
Video/DVD*	32	58	4.3	<0.0001
Awareness Raising Campaigns*	41	55	2.2	0.027
Discussion Groups*	55	74	3	0.003
Letters in the post*	40	53	2.1	0.040
Face-to-face advice	68	61	1.2	0.24
Telephone Help Lines	64	61	0.5	0.62
Press Releases	53	58	0.8	0.43
Books	38	48	1.6	0.11
Website	90	87	0.8	0.44
Email	74	71	0.5	0.60

**significant at the p<0.05 level*

Table 3b: Primary information channels that were ranked most important by European/North American organisations(10% or greater for at least one of Europe or North America)

	Europe (%)	North America (%)	z-value	*p*
Annual patient meetings/summits/conferences	25	16	1.6	0.1
Websites*	17	33	3.2	0.001
Telephone help lines	10	3	1.9	TNA
Face-to-Face advice	6	11	1.6	0.115
Awareness raising campaigns	9	10	0.3	0.786

TNA Test not applicable

Table 3c: Proportion of information sources available online

	Europe (%)	North America (%)	z-value	*p*
	54	67	2.0	0.042

4. GATHERING INFORMATION

Table 4a: Channels through which information was gathered for provision to patients

	Europe (%)	North America (%)	z-value	*p*
Conferences/seminars*	61	74	2.1	0.036
Board of trustees/medical subcommittee	60	57	0.5	0.63
Other health professionals	60	62	0.3	0.750
Medical journals*	54	69	2.4	0.019
From Patients known to us	48	55	1.1	0.28
General Web searching	46	41	0.8	0.43
Academic Bodies*	45	62	2.7	0.008
Other Patient Organisations*	43	63	3.1	0.002
Government bodies*	38	52	2.2	0.03
Public Media	28	29	0.2	0.86
Online Discussion Groups*	16	30	2.9	0.004
Blogs	2	4	1.1	TNA
Patient survey	67	62	0.8	0.41
Patient focus groups	56	64	1.3	0.21
Patient feedback forms	57	60	0.5	0.64

**significant at the p<0.05 level, TNA Test not applicable*

5. STANDARD SETTING FOR INFORMATION

Table 5: Approaches organisations used to check/maintain quality and veracity of information provided to patients

	Europe (%)	North America (%)	z-value	*p*
Regularly updated their information	66	71	0.8	0.41
Patient feedback	61	60	0.2	0.87
Medical/advisory group check	48	60	1.9	0.06
Through membership of umbrella organisation	41	40	0.2	0.87
Board of Directors check	22	29	1.3	0.19
Aligned Stakeholder body check	16	16	0.0	1.00
Online Certification Body check*	14	24	2.2	0.03
Pilot studies of patient opinions	13	12	0.2	0.82

6. USAGE OF INFORMATION

Table 6a: Use of website as a social media tool

	Europe (%)	North America (%)	z-value	p
'Most'/'All' of people affected by cancer used website as social media tool*	66	85	3.2	0.002

**significant at the p<0.05 level*

Table 6b: Use of different social media tools to access information

	Europe (%)	North America (%)	z-value	*p*
Websites*	67	84	2.9	0.004
Email	43	71	4.4	<0.0001
Electronic Newsletters	21	42	3.9	0.0001
Social Media	13	33	4.4	<0.0001
Internet chat fora	10	20	2.5	0.013
Internet blogs	8	15	1.9	0.504
Wikis	7	5	0.6	TNA
Online petitions	6	4	0.7	TNA
Photo/video sharing	4	8	1.5	TNA
Live webcasting	2	16	5.9	TNA
Podcasts	1	0	0.8	TNA
Webinars	1	11	5.5	TNA

TNA Test not applicable

Table 6c: Populations for which accessing the Internet was deemed difficult

	Europe (%)	North America (%)	z-value	*p*
Older people	95	95	0	1
Those who do not speak the main language of the country	77	72	0.9	0.36
Ethnic minorities	67	65	0.3	0.74
Those with disabilities	66	61	0.8	0.41
Women	51	41	1.6	0.12
Men	49	45	0.6	0.53
Carers	48	41	1.1	0.27
People of working age	38	27	1.8	0.08
Younger people	20	11	1.8	0.08

Table 6d: Barriers to seeking online information

	Europe (%)	North America (%)	z-value	*p*
Limited computer skills**	85	74	2.3	0.02
Limited access to Internet**	84	67	3.5	0.0005
Limited access to computers/smart phones	76	83	1.3	0.197
Language	64	55	1.5	0.146
Lower income*^	41	55	2.2	0.027
Literacy problems	61	69	1.3	0.199
Doubts about trustworthiness	35	39	0.7	0.515
Fears about privacy	34	44	1.6	0.102
Disability	33	39	1.0	0.322
No need/faith in medical profession*	30	53	3.8	0.0001

**significant at the p<0.05 level*

***higher barrier Europe*

^higher barrier North America

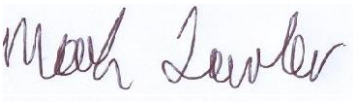
***Conflict of Interest statement**

4th January 2018

Dear Editor

In relation to the manuscript entitled **Mapping the cancer patient information landscape: a comparative analysis of patient groups across Europe and North America** none of the authors report any conflict of interest in relation to this work

Yours sincerely



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